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THE ACCURACY OF A PROXY'S SUBSTITUTED JUDGMENTS
FOR INDIVIDUALS WITH AND WITHOUT ADVANCE DIRECTIVES

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THESIS

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The University of Texas Graduate School of Biomedical Sciences
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By
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WITH AND WITHOUT ADVANCE DIRECTIVES

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DEDICATION

This thesis is dedicated to the ones I love and hold dear. The ones who through their love, influence, and guidance I have developed a passion for life and thirst for knowledge.

To my parents, Gaynel and Annie Patterson, who raised me, loved me, and influenced my love for nursing. My dad instilled in me a love of the natural sciences at an early age. My mom has provided me with an unequivocal example of what a nurse should be.

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THE ACCURACY OF A PROXY'S SUBSTITUTED JUDGMENTS
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This study examined and compared individuals' perceived end-of-life choices to those of the person acting as their proxy in the event they are no longer able to make decisions for themselves. Whether or not the presence of an advance directive (AD) document influenced the concordance between individual and proxy also was investigated.

The theoretical framework is congruity and relevance of communication. An individual must communicate to the proxy in such a way that the information given becomes

relevant to the proxy in order that subsequent decisions would be congruent with that of the individual.

The research questions examined for this descriptive study are:

1. How do the judgments of individuals with an AD compare with the substituted judgments of their designated proxy?

2. Are the substituted judgments of the proxies of individuals with an AD more accurate than the substituted judgments of proxies of individuals without an AD?

The sample ($n=74$) consisted of individuals 54 years or older and their respective proxies. The sample was drawn from two Air Force retirement communities in San Antonio, Texas and the retired community of Seguin, Texas. Participation was voluntary. The sample was divided into two groups: 1) those with an advance directive, and 2) those who did not have an advance directive.

Scenarios were given to the participants with specific treatments they could accept or reject. The proxies were instructed to answer as they believed the person they represented would in that situation. Concordance for each group was evaluated by assessing percent agreement, kappa coefficient for concordance beyond chance, and McNemar Test for the directionality of discrepant responses. T-tests and odds ratios with 95% confidence intervals were used to evaluate the chance of agreement if an AD was present. ANOVA was used to determine if the reported number or level of discussions had an impact on concordance.

No significance of concordance was noted for the group with AD ($\text{kappa} \leq 0.35$, percent agreement range, 31%-100%). The group without AD, however, did have significant concordance for specific treatments in Situations A, C, and D ($\text{kappa} > 0.40$, percentage

agreement range, 33%-100%). Directionality of discrepant responses in both groups was to provide undesired treatment. The group with AD scored consistently higher than the group without AD, and the odds of agreement increased in the presence of an AD. The chance of concordance increased with an increase in the number of discussions with one's proxy. These results reflect a slightly higher percentage agreement and concordance than reported in similar studies. The higher concordance rate of the individuals without AD for specific treatments implies that the presence of an AD does not make a difference in agreement between individual and proxy. Yet, the results of the t-tests and odds ratios for the general scenarios indicates that there is greater chance of agreement if one has an AD. The advance directive document may guide conversations and enhance relevance for the proxy.

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Chapter I

Introduction

Advance directives (AD) have been heralded as a means of maintaining autonomy and having control over the health care received once an individual is no longer able to communicate due to incapacitation. The AD document may provide specific written instructions or designate a proxy to make decisions in one's stead. AD generally pertain to terminal or irreversible conditions, but in the form of a power of attorney may be used anytime a person is incapacitated. The substituted judgment of the proxy should approximate that of the individual for whom the proxy is making decisions.

Purpose

The purpose of this study is to examine and compare individuals' perceived end-of-life choices to those of the person acting as their proxy in the event they are no longer able to make decisions for themselves.

Background/Significance of Study

Since the passage of the Patient Self-Determination Act (PSDA) in 1991, the Advance Directive (AD) has been promoted as a way to inform others, especially the physician or family, of what medical measure individuals may or may not want taken if they are unable to make those decisions for themselves. The AD is a legally binding document and may take the form of a Living Will (LW) or Durable Medical Power of Attorney (POA) depending on which state issues the document. In Texas, persons may have a LW or a POA or both as their AD documents. The LW, in Texas, requires two "uninterested" witnesses. It is considered valid when people are diagnosed with a terminal illness or other irreversible condition, and cannot

make decisions for themselves. The LW may be as specific as a person desires and may designate a proxy to make healthcare decisions for that person. Individuals may verbally revoke or changed their LW at anytime. The POA designates a proxy to make decisions in the event of incompetence and requires notarization for validation. The POA may be restricted to certain situations, e.g., end-of-life decisions, or may take effect during any period of time a person may experience incapacity. (Choice for Dying, 1997, March 25)

Since the advent of the AD, several studies were done to determine its effectiveness and to identify possible reasons for its shortcomings. While 80-90% of surveyed individuals support the concept of ADs, only 15-25% have completed one (Madson, 1993; Emanuel, Barry, Emanuel, and Stoeckle, 1994). Procrastination is reported as the major reason for not completing a document (Sulmasy, Haller, & Terry, 1994). Also cited was a belief that the family has the innate authority to make decisions for their loved one, and a general denial of sickness and death (Dooley & Marsden, 1994). Some feel the AD would not make a difference in the care received (Cox & Sachs, 1994). The difficult language used in AD documents contributes to both lack of completion of or non-adherence to an individuals' wishes (Ott and Hardy, 1997). Vagueness of the wording in the document provides poor communication and allows for misinterpretation or non-adherence (Walker, Schonwetter, Kramer, & Robinson, 1995). The primary obstacle for non-adherence to an individuals' wishes for treatment is identified as communication of those wishes to those who would be responsible for fulfilling them (Emanuel & Emanuel, 1989; Cox & Sachs, 1994; Hare, Pratt, & Nelson, 1992; Seckler, Meier, Mulvihill, & Cammer Paris, 1991; Sulmasy et al., 1994). The AD document's existence

or its content is often not communicated to the physician, family, or friends (Cox & Sachs, 1994; Watne, 1995).

Traditionally, physicians have looked to the family for decisions when patients are no longer able to do so for themselves (Brett, 1991). This is an informal use of proxy where the patient does not chose the decisionmaker. The family, though, may not be aware of what choices the patient would make in that situation. Arguments exist for the formal use of a proxy, preferably by POA, to be used as an adjunct to the written instructions of a LW to ensure that one's wishes are followed (Brett, 1991; Cox & Sachs, 1994). Yet, the ability of the proxy to make accurate substituted judgments has been questioned (Seckler et al., 1991; Hare et al., 1992; Sulmasy et al., 1994). These studies have reflected only a 59-80% accuracy of decisions in relationship to given scenarios and have found no correlation of increased accuracy with ADs. Lack of communication between an individual and proxy was cited as the reason for the lack of concordance. The studies either did not reflect the number of participants with an AD or had a low percentage of participants with an AD which might have influenced the correlation between accuracy and the presence of AD documents.

For nurses, a primary concern is the maintenance of a patient's autonomy. Nurses support and promote the use of ADs (Meyer, 1993). The AD allows the patient to maintain autonomy through delegation to a trusted proxy. Nurses may need to intervene to promote the communication between the patient and the proxy to facilitate accurate substituted judgments.

Problem Statement

High (1994) stated that research is needed to determine if the presence of an AD increases the chance of communicating an individual's preferences regarding treatment.

Sulmasy et al., (1994) stated that little is known regarding the accuracy of the substituted judgment of the proxy and echoes the call for further research. This study attempted to determine whether the accuracy of substituted judgments is influenced by the presence of an AD by comparing the substituted judgments of the designated proxy of a person with an AD and the substituted judgments of an appointed proxy of a person without an AD.

Research Question

1. How do the judgments of individuals with an AD compare with the substituted judgments of their designated proxy?
2. Are the substituted judgments of the proxies of individuals with an AD more accurate than the substituted judgments of proxies of individuals without an AD?

Theoretical Framework

The theoretical framework of the study is based on the concepts of the communication state, congruity and relevance in communication. Carl Rogers (1961) defines communication as occurring “when we listen with understanding...to see the expressed idea and attitude from the other person’s point of view, to sense how it feels to him, to achieve his frame of reference in regard to the thing he is talking about” (pp. 331-332).

Nielson (1970) defines communication in two broad categories. Category one involves direct communication, to have a specific purpose or message that is intended to elicit a response. The second category involves nondirect communication and is based on commonalties of the participants for understanding. The second category overlaps the first. For example, with end of life discussions, direct communication could be in the form of an advance directive naming a proxy, giving specific instructions for desired procedures, and face to face

discussions of specific wishes regarding procedures. Underlying this direct communication will be nondirect communication of value systems, commonalities, and casual conversation. Nondirect communication would be a person who does not designate a proxy or directly discuss any of the issues related to end of life decisions. A proxy would then base any decisions on what is known of the person based on the proxy's value systems, casual conversation with the person, or common backgrounds of the two individuals.

Communication state. Direct communication implies a communication state. Millar and Millar (1976) define the communication state as "when two or more persons capable of processing symbolic information and assigning meaning realize that they are understood and understand each other, i.e., realize they have shared meaning." A communication state cannot be assumed. If one person accurately sees object "B", and another person accurately sees object "B", it is not safe to assume that they both perceive the object in the same way. Different needs, purposes, backgrounds, attention levels, and perceptive abilities influence how one sees or understands what is seen or heard. A communication state is situation and content bound. The situation sets expectations about what will be perceived, the most likely interpretations, relationships, and behaviors. The content or meaning of one subject may be the same for the participants, but one cannot assume another issue will result in shared meaning. Creating a communication state does not guarantee agreement between participants, only a mutual recognition of understanding.

Congruity. For agreement, there must be congruity of meaning. The concepts of balance, congruity, and dissonance as described by Zajonc (1960) have a commonality that "thoughts, beliefs, attitudes, and behavior tend to organize themselves in meaningful and

simple ways.” Congruity exists when the attitudes and assertions toward a subject are similar. Dissonance is the conflict of cognitive elements. Balance falls somewhere between congruity and dissonance. A balanced state can be achieved by a “strain toward symmetry” which leads to a communality of attitudes or meanings between two people. Communication is influenced so that the attitude of the two people toward a subject becomes more congruent. The degree of congruency achieved is dependent upon the conditions under which attitudes are acquired, the message received, and the relationship of the subject to an individual’s needs and fears. If the subject is one that is feared and avoided by an individual, a change in attitude or meaning may not be possible. An example given by Zajonc is no matter how much a child may like Popeye, he cannot be convinced to eat spinach.

Relevance. Relevance theory (Sperber & Wilson, 1986) deals with understanding the meaning of the message by the listener. Relevancy theory is based on two other models, the coding model and the inferential model. The coding model is associated with semiotics, words and other symbols convey meaning. The inferential model proposes that meaning is more than simply transferred but inferred by evidence in the message. Relevance theory combines the two models to help explain the complexity of human communication. Human communication involves more than simple association between a symbol or stimulus and a referent, it involves intention and purpose. The sender must get the intention across and the receiver must understand that intention accurately. The intention is interpreted by making inferences based on one’s own knowledge, as one can not know what the other person knows. There are two level of intent: (a) the informative intention, to have the listener become aware of something; and (b) the communicative intention, to have the listener become aware of the purpose of the

statement. Inferring an intention is dependent on the context, or assumptions used to understand a message. Difficulty in understanding arises because everyone has a different cognitive environment, a different set of assumptions on which to understand one's experience. What one already knows is used to determine what is relevant to that person. The combination of old and new information that is relevant strengthens the existing assumptions. The degree of relevance is dependent upon the context and the cognitive effort required to process the information. The resulting change in the cognitive environment may be concrete, a factual claim, or vague, a feeling or impression.

In conversation, the speaker has two primary tasks, to get your attention and to present a relevant message for the sender. The listener then must figure out the meaning of the message. If the message is ambiguous, the listener needs to resolve the ambiguity, perhaps by asking for clarification.

The principle of relevance is to determine the actual intent of the speaker. Conversation often involves implied content and the listener must infer the intention from what is known about the speaker and the context in which the message is received. If the direct message is not relevant, the listener may explore the meaning or reject the message as irrelevant.

Summary of Theoretical Framework. In order for one to communicate effectively with another, direct or purposeful, communication must take place. The speaker must get the attention of the listener and present his message in a way that it becomes relevant for the listener. The listener must take in the message and based on what is known by that listener, determine its relevance and meaning. If the meaning is unclear, the listener must clarify with the speaker as to the purpose and meaning of his message. With nondirect or nonpurposeful

communication, what is said by the speaker is left to interpretation by the listener and based upon the cognitive environment of the listener, may or may not be interpreted correctly. The inferred message may be ambiguous because of the lack of other signals or messages.

Relevance for the listener may or may not exist. If the subject of the message is one that the listener wishes to avoid, the message may be considered irrelevant unless the speaker can find a way to make it relevant for the listener.

In the discussion of end-of-life decisions, a speaker must get the proxy's attention. The content that is presented and the context in which it is presented play an important role in the way the message is received. An AD provides a focal point on which to build a discussion. The speaker must be direct or purposeful, not vague, in order for the listener to understand the relevance of the message being delivered. The proxy must realize the significance of what is said by the speaker and clarify the meaning of the message so that it may be understood. If understanding exists, substituted judgments of the proxy should accurately reflect the judgment of the speaker. Figure 1 illustrates this process.

Definitions

1. *Advance directive* is defined as a living will and/or a durable power of attorney.

This definition is congruent with the state laws of Texas where the study will be conducted.

2. *Designated proxy* is an individual one trusts and has asked to make decisions in the event of mental incapacity. A proxy may be a significant other, family member or close friend.

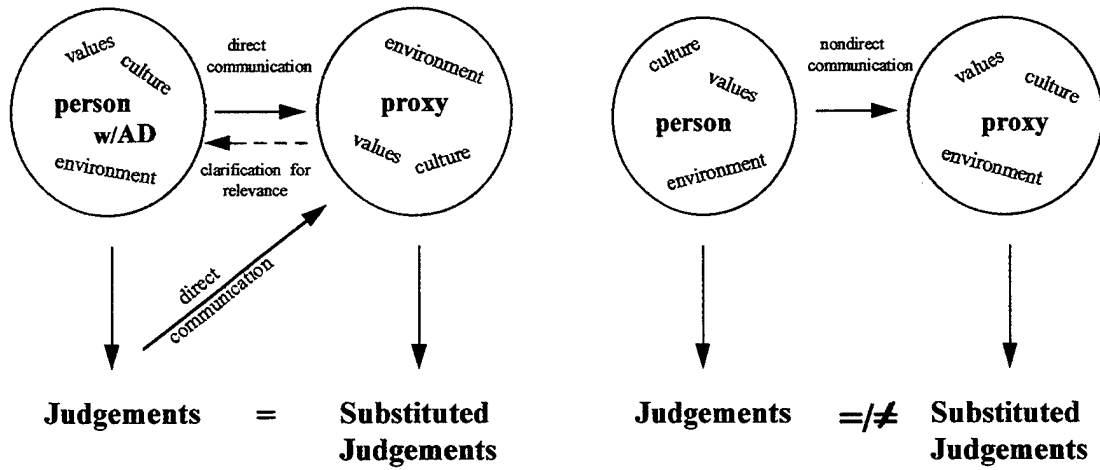
3. *Appointed proxy* is an individual who is chosen to make decisions for another who has become incapacitated and can no longer make decisions for themselves. The appointed proxy is usually a close family member as designated by state law, e.g. spouse, parent, adult

Figure 1

MODEL OF COMMUNICATION OF SUBSTITUTED JUDGMENTS

A person with an AD chooses a proxy. Trust, common values, and the environment affect that decision. The person through direct communication informs the proxy of the choice an of his/her preferences regarding medical should become incapacitated. Meaning verified and relevant to proxy. Thereby enabling the proxy to make substituted judgments.

The person without an AD becomes incapacitated and a proxy, usually a family member, is chosen to make the decisions. There has been no direct communication of the preferences of medical care if he desired. Relevance to the proxy is questionable. Subsequent judgments may or may not be accurate substitute judgments, on the person's behalf.



child, or as assigned by a court.

4. *Judgment* is the decision an individual would make in given situations.

5. *Substituted judgment* is a decision made by the designated or appointed proxy that reflects the judgment made by an individual in the same given situation.

6. *Accuracy* is the similarity of a proxy's substituted judgment when compared to the judgment of the person they represent.

Assumptions

1. Persons with an AD document discuss their perceived end of life choices for medical treatment with their designated proxy.

2. Persons without an AD document may or may not discuss end of life issues with persons who may act as their proxy in the event of incapacitation.

Limitations

There are a limitless number of choices that can be made in any given situation and it is not practical or conceivable to address all of them. The scenarios chosen only reflect four possible situations and is void of variables that could influence the actual decision being made such as the emotions involved in such a situation, a physician's or other health care worker's input, available resources, or family support. While the use of given scenarios and a questionnaire will limit the number and type of choices that will be made, it should reflect the ability of a designated proxy to make substituted judgments.

The study was limited to a convenience population solicited from Air Force Retirement Communities and the retired community of Seguin, Texas. The population was over the age of

54, predominately caucasian, married, college educated, and Protestant. This limits generalization of any findings to similar groups.

Data collected regarding communication was self reported and descriptive in nature. There were no controls for communication prior to the study. The participants were asked not to discuss their responses as they completed the questionnaire. The resulting analysis may not truly reflect the effect of communication on agreement between an individual and proxy.

Chapter II

Review of the Literature

The review of the literature covers three areas, Advance Directive (AD) documents, the use of a proxy, and the variables that can effect the completion of an AD document and/or the communication of one's medical preferences to their proxy. Pertinent studies are identified and reviewed.

Advance Directive Documents

Emanuel & Emanuel (1989) addressed the issue of communication of end-of-life treatment preferences with the physician. They proposed the Medical Directive (MD) as an alternative to the Living Will (LW). While the LW is vague and often difficult to apply, the medical directive is specific, focusing on diagnostic and therapeutic interventions. Since its introduction, the MD has been researched as a tool to determine if it can indeed reflect the choices one would make (Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994; Emanuel, Barry, Emanuel, & Stoeckle, 1994; Alpert, Hoijtink, Fischer, & Emanuel, 1996) and to evaluate its usefulness in facilitating communication with the physician and family (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; Emanuel & Emanuel, 1992). The research is reflective of the authors claims. It has not been adopted in Texas as an advance directive document, but could be very useful in communication with individuals to assist in decision-making or to communicate their preferences for treatment to the physician, family, and/or proxy.

Another attempt at improving the communication of end-of-life treatment preferences, Doukas & McCullough (1991) proposed the use of the Values History as an adjunct to the

advance directive. The author proposes the Values History enhances the autonomy of the individual through an evaluation and clarification of the expressed values used in health care decision-making. The Values History has two parts: an explicit identification of values and the articulation of advance directives based on the individual's values. The greatest barrier to the use of the Values History is the time required to do an adequate evaluation. The first part is supposed to identify the individual's values explicitly, yet it asks for open ended responses that could be vague or misleading depending on interpretation. The directives section does list specific treatment choices but not in relation to a possible situation. The tool has the potential to be cumbersome and ineffective if one is not trained in its use.

The need for values clarification is valid. In a revision of the Medical Directive (Alpert, et al, 1996), Emanuel and Emanuel added a section to identify goals for care. The goals for care, like the Values History, aids in determining what quality of life means for an individual.

Use of Proxy

Brett (1991) supports the use of proxy decision-making as the most effective means of dealing with the vagueness present in most advance directives. Proxy decision making is a formal acknowledgment of the traditional way of making decisions for the incapacitated patient--enlisting the guidance of the patient's family or other close associates. A proxy is an individual one designates to make one's treatment decisions in the event of coma, incompetence, or other mental or physical incapability of communication. There are two accepted standards of proxy: "substituted judgment" and "best interests". Substituted judgment asks the surrogate to make the decision the patient would make in that particular situation. This requires the surrogate to know the patient's expressed preferences while

decision-making capacity is intact. Best interests are when the patient's preferences are not known and the surrogate must choose the course of action that promotes the patient's interest. The limitations of a proxy lie within the amount and quality of communication between the person who designates the proxy and the proxy. If an individual states his preferences vaguely or not at all, substituted judgment becomes problematic. A proxy needs to be aware of the person's wishes in order to carry them out.

Cox & Sachs (1994) also argue for the use of a proxy for health care decision- making by designation through POA. A proxy is not limited by terminal illness as is the living will, rather, the proxy can make medical decisions in any situation involving a loss of mental capacity, including temporary incapacity. The author states the need for an individual to communicate adequately his decisions to a trusted family member or friend who will comply.

The ability of a proxy to perform substituted judgment is debatable. A study done by Seckler, Meier, Mulvihill, & Cammer Paris (1991) questioned the accuracy of the substituted judgments of a proxy. Using a hypothetical scenario involving cardiopulmonary resuscitation, the authors compared the decisions of competent chronically ill elderly patients with the surrogate decisions made by primary care providers and close family members. It was found that the surrogates were only 59-80% accurate in their substituted judgments. Interestingly the patients predicted that both the physicians (90%) and family members (87%) would accurately reflect their wishes. Results supported lack of communication as a possible cause of the discrepancy. Only 16% of the patients had ever discussed their resuscitation preferences with their family members and only 7% had discussed their preferences with their physician. It was

not identified in this study if the individuals had advance directives or if any of the family members questioned were in fact the designated proxy of the individual.

Ouslander, Tymchuk, & Rahbar (1989) looked at the health care decisions of elderly long-term care residents and their potential proxies. The residents were presented a series of vignettes and asked what decision they would make regarding each vignette. The vignettes were then mailed to the resident's closest relative, his/her primary nurse, physician, and social worker. The results showed the greatest agreement was between the residents and their family members, yet those results reflected earlier studies of only 60-80% agreement. The study did not identify which residents, if any, had advance directives and if the closest relative was the designated proxy. The authors did state that most elderly long-term care residents do not have a POA and that treatment preferences are often unknown to family members or physicians. The authors propose the development of strategies to ensure the validity of decisions made by proxy. The use of a POA is suggested as a starting point, but the authors voice a need for explicit and repeated discussions of specific types of health care decisions with the designated proxy.

Hare, Pratt, & Nelson (1992) echo caution in the use of proxy decision-makers. Their study addressed the level of agreement between patients and their self-selected surrogates. Vignettes were used to solicit responses from the pairs of participants. The responses of the pairs were in agreement only 70% of the time. The population was randomly chosen from a clinic population. Those who agreed to participate were asked to choose someone they would trust to make decisions for them. Of the population only 13% had completed a formal advance directive prior to the interview. The authors state they did not know how much informal

communication took place between the participants in anticipation of the interview. The importance of the effective communication between an individual and their chosen proxy prior to incompetency is underscored by this study.

High (1994) discussed some of the issues related to the use of a surrogate decisionmaker. His commentary cited studies of the elderly where 95% stated they did not feel they needed ADs as they were confident their families could make the necessary decisions. High also cited a study from 1986 that found elderly patients were more interested in who was to make their decisions rather than how those decisions reflected their own views. High points out that most states have "surrogate/family decisionmaking" policies that places the priority for health care decisions on the family. He argues that if research does not show that ADs are effective in communicating a person's preferences and increasing the accuracy of substituted judgments, the concept of ADs may need to be rethought. Perhaps ADs should only be promoted for those who have very specific or unusual preferences; do not want their family to serve as substitute decisionmakers or have disagreements with family; or have no family or other sanctioned surrogate available.

Sulmasy, Haller, and Terry (1994) questioned the accuracy of substituted judgments. For their study, the surrogates were chosen by the state based hierarchy used to determine appropriate surrogates. The patient and the surrogate were presented with the three scenarios and eight modes of medical intervention modified from the "Medical Directive" developed by Emanuel & Emanuel. The authors omitted the option of an "unsure" response to avoid subjectivity in the interpretation of the response. For 86% of the participants, the surrogate chosen by the investigator according to the state based hierarchy was the surrogate the patient

would have chosen to speak for him or her if given a choice. The agreement between the patient and the surrogate ranged from 57% to 81%. The patient and surrogate that had indicated prior discussions about the patient's preferences showed an increased level of accuracy. The authors did not find that AD documents were associated with accuracy of the substituted judgments. The presence of a POA does not guarantee that discussion of the document or the patient's preferences takes place. Overall, the results reflected that the substituted judgments by the surrogates was better than those expected due to chance alone. Sulmasy, et al, feel that if further research corroborates their findings, that physicians could more comfortably urge surrogates to give their "best estimate" as the surrogates are more likely to be right than wrong in their judgments.

Extraneous Variables. There are many extraneous variables that can effect the health care decisions of an individual, the completion of an AD, and the communication of those decisions to their designated proxy. Cox & Sachs (1994) cite cultural, socioeconomic, and educational backgrounds as factors that influence the completion and implementation of an AD. Doukas & McCullough (1991) discuss the effects of issues such as religion, quality of life, and expectations of the individual. Madson (1993) identified society's desire to avoid death and the reliance on family members to make decisions as probable causes for lack of communication. Emanuel, et al, (1994) echo this, as they find some individuals that simply knowing who will make decisions for them is adequate. An editorial by Loewy & Carlson (1994) emphasize that the "AD cannot be allowed to substitute for conversation."

Summary.

The review of the literature provides a broad view of ADs and the perceived advantages and the identified shortcomings in the application of its concepts. The use of a proxy, whether formal or informal, is an accepted way for medical members to ascertain what medical treatment should be pursued in treatment of individuals who are no longer capable of making those decisions themselves. However, the ability of the proxy to make decisions that reflect the preferences of the individual has been questioned. Lack of communication was identified as the primary reason for the lack of accuracy. The AD is promoted as a means to facilitate communication to a person's family, friends, and physician, yet, no evidence has been established to support this. This study will attempt to determine if the presence of an AD document increases the accuracy of substituted judgments. Chapter III will describe the methods, research design, population, and instruments to achieve this purpose.

Chapter III

Methods

Research Design

This was a descriptive study comparing the choices of persons with and without an advance directive and the substituted judgments of their chosen proxies in given situations. The situations were presented in a questionnaire format depicting four given scenarios and specific treatments one could accept or refuse. The questionnaires were completed by persons both with and without advance directives and by their selected proxy.

Instruments

The scenarios were taken from the Medical Directive (Appendix A) developed by Emanuel and Emanuel (1995). The Medical Directive has been published in full and is available from the authors and in the public domain. The Medical Directive consists of six hypothetical scenarios with nine possible interventions. Choices for each intervention are want, do not want, want a trial period of each intervention, or undecided. The scenarios were chosen for their “paradigmatic nature”, encompassing the spectrum of types of mental incompetence and representing circumstances that have prompted legal cases. Situation A describes an irreversible coma or vegetative state with no terminal illness. Situation B describes a coma with a small and uncertain chance of recovery. Situation C involves some brain damage causing mental incompetency and a terminal illness. Situation D involves some brain damage causing mental incompetence without any terminal illness, such as dementia. Situation E is determined by the individual. It calls for the individual to describe a situation that is important to consider in relation to their current health status. Situation F is also determined by the patient and

reflects the current health status with a curable life threatening illness, such as pneumonia.

Each situation includes a values survey to give insight to the individuals decisionmaking process. The goals for care are:

- a) Prolong life; treat everything
- b) Attempt to cure, but reevaluate
- c) Choose quality of life over longevity
- d) Provide comfort measures only
- e) Other, please specify.

Subjective responses by the participant are open to interpretation by the investigator.

To avoid bias in the collection of the data, scenarios E and F, the undecided response to interventions, and the "other" goal for care were omitted from the instrument for the purposes of this study to avoid misinterpretation of the responses by the investigator (Sulmasy et.al., 1994). For analysis the "trial" treatment will be considered as "I want treatment." (Appendix B)

Internal and external validity were estimated by psychometric analysis in a study by Alpert, Hoijtink, Fischer, & Emanuel (1996). The complete six scenario version was distributed to physicians, while the four scenario version was distributed to outpatients and the general public. High inter-item reliability was demonstrated by the Kuder Richardson-20 for outpatients (.98), physicians (.97), and the public (.93). Construct validity was demonstrated in relations among specific treatment preferences and between treatment preferences, illness scenarios, and goals for treatment. The study of the separate populations supports its external validity. The authors concluded that the "treatment items constitute a highly reliable scale that can be used in further empirical research regarding life-sustaining treatment." (p. 1057)

Sample and Setting

The questionnaires were distributed to a convenience sample solicited from the military retirement centers, Air Force Village I & II (see appendix C for letters of agreement to participate.) in San Antonio, Texas and from the community of Seguin, Texas. A total of 74 persons and their designated proxies participated. Fifty-two individuals had an AD and twenty-two individuals did not have an AD. The designated proxy for those individuals who did not have an AD was chosen by the individual. The sample size provided a power analysis of 0.8 with an alpha of 0.05. There is an expected concordance rate of 60-80% as cited in the literature (Emanuel & Emanuel, 1989; Seckler et. al., 1991; Hare et. al., 1992; Sulmasy et. al., 1994). Inclusion criteria were age of 55 years or greater and availability of a designated or appointed proxy to complete the questionnaire. The subjects were English speaking and were able to read and complete the questionnaires without assistance.

The retirement villages are populated by retired Air Force military officers and their spouses. The education level of the individuals and their proxies is predominately a graduate degree or above. Ethnic background is predominately caucasian with Catholic or Protestant affiliation. Upon becoming residents of Air Force Village, each participant had received counseling regarding advance directives and are given the opportunity to complete one at the facility at no charge. As retired military officers, medical care is one of the benefits of retirement, and all residents have access to health care.

The community sample was predominately caucasian with an education level ranging from grade school to a postgraduate degree. No data were collected regarding knowledge of advance directive documents or access to health care. Accessibility to services for obtaining

advance directive documents vary with the individual. The local hospital offers information on ADs and provides forms upon request. AD forms are also available on the internet for those with computer access. The LW requires only two signatures of individuals not involved with health care decisions of the individual. The POA requires notarization and may require the assistance of a lawyer and involves some cost.

Procedure

At Air Force Village I & II , an invitation to participate and explanation of the study (Appendix D) was distributed through the facilities' newsletter with a similar announcement posted in each facility on the bulletin board designated for upcoming events. Volunteers signed up for participation at each facility. In Seguin, participation was solicited by word of mouth through acquaintances of the investigator.

A packet consisting of the consent form, demographic information (Appendix E), and the questionnaires were distributed to all participants by the investigator. Questionnaires were completed in small groups of three pairs or less. All forms were reviewed with the individuals to insure understanding and consent. Participants were asked to not discuss any section of the questionnaire during completion of the questionnaires.

Ethical Considerations

Confidentiality of the participants of the study was maintained. Informed consent was obtained and a numbering system used to identify and pair the responses of the individual and chosen proxy. Competency of the participants for consent was assumed based on the ability to read the consent form and correctly fill out thier name, address, phone number, current date, and date of birth. Accuracy of the information provided was confirmed by the facility's records

at Air Force Village I & II and by the person's driver's license for those solicited from the community. The questionnaire took 15-20 minutes to complete. The responses of the questionnaire were reviewed with participants only at their request.

The benefits identified by participants in the study were an increased awareness of the need to communicate one's choices regarding end of life decisions to their designated or potential proxy and information on which to base those conversations. No adverse effects to the participants were expected or noted.

Data Analysis

T-tests were used to determine the homogeneity of the two populations, AFV and Seguin. The population was divided into two groups, those with an advance directive and those without an advance directive. The concordance for each group was evaluated by assessing percent agreement, kappa coefficient for concordance beyond chance and the McNemar Test for the directionality of discrepant responses. Agreement was evaluated for each scenario, each scenario-specific treatment, and across the four scenarios. The results of the two groups were compared using t-tests and odds ratios with 95% Confidence Intervals to determine if the presence of an AD increased the chance of agreement. ANOVA was used to determine if the reported number or level of discussions had an impact on the concordance in each scenario and over the four scenarios.

Summary

Chapter III has described the sample criteria, procedures, and analysis to be used. The instrument was described and its reliability discussed.

Chapter IV

RESULTS

Sample Demographics.

Population. The sample consisted of individuals with or without an advanced directive and their respective proxies. Demographic data collected from the individuals included factors identified in the literature that may influence one's decision to complete an advance directive. These factors were gender, age, marital status, ethnic background, religious preference, presence of a chronic illness, hospitalization within the last year, and their current health status. Demographic data collected from the proxies included gender, age, marital status, ethnic background, and religious preference. Data related to the presence and communication of the advance directive or one's wish regarding end-of-life health care was collected from the individuals as to whom they discussed it with, the relationship to the proxy, and how often and at what level they had communicated. Other information solicited from the individuals was an open question regarding why they did or did not have an advance directive.

The populations of the sample solicited from Air Force Village I & II and that from the community of Seguin were compared for homogeneity. A t-test was used to compare the ages of the two populations ($t\ 3.91$, $df\ 72$, $p=.000$). It was noted that the mean age of the Seguin sample was slightly lower than that of Air Force Village, but within the accepted age group targeted for the study. Crosstabulations and Pearson Correlation were used to compare the remaining variables with no significant differences noted. The population was treated as homogenous and divided into two groups according to the presence of an advance directive.

The mean age of the individuals was 73.9 years. Age ranged from 54 to 90 years. The mean age of the proxies was 68.9. Ages ranged from 42 to 84. Table 1 presents a breakdown of the sample by age groups. The majority were married, Caucasian, college educated, Protestant, and reported their current health status to be good. Table 2 summarizes the characteristics of the sample. Chronic illness was reported by 28.4% (n=21) of the individuals and 14.9% (n=11) reported being hospitalized in the last year.

Communication Variables. Those not having an AD represented 29.7% of the sample. Those having an AD represented the remaining 70.3%. Of those having an AD, the majority had both a living will and a power of attorney. The spouse was the most common relationship of the proxy and the person with whom discussions had taken place. The reported level of discussion with the proxy was predominately purposeful or in-depth and specific. Table 3 provides a summary of the types of AD, relation to proxies, and type and amount of discussions.

Fifteen participants identified reasons for not completing an AD document. Procrastination was the most common reason cited (n=9). Other reasons were personal choice (n=1), not informed (n=1), not fully decided (n=1), spouse not cooperative (n=1), no particular reason (n=1), and had discussion with spouse and children (n=1). Those responding with reasons for completing an AD (n=15) reflected the need for control over their situation, a desire for their decisions to be carried out, and concern for their family, giving guidance and eliminating guilt.

Table 1

AGE OF THE SAMPLE

Age	<u>Individuals</u>		<u>Proxies</u>	
	N	%	N	%
46-50	~	~	1	1.4
51-55	~	~	6	8.1
56-60	2	2.7	2	2.7
61-65	7	9.5	9	12.2
66-70	15	20.2	15	20.3
71-75	17	23	15	20.3
76-80	17	23	11	14.8
81-85	11	14.9	11	14.8
86-90	5	6.7	~	~

Table 2

CHARACTERISTICS OF THE SAMPLE

Variable	<u>Individuals' Data</u>		<u>Proxies' Data</u>	
	%	n	%	n
Gender				
Male	43	32	47	35
Female	57	42	53	39
Marital Status				
Single	2.7	2	1.4	1
Married	83.8	62	94.6	70
Divorced	1.4	1	2.7	2
Widowed	9	12.2	1.4	1
Education Level				
Grade School	5.4	4	2.7	2
High School	17.6	13	16.2	12
Undergraduate	31.1	23	35.1	26
Graduate+	41.9	31	43.2	32
Ethnicity				
Caucasian	86.5	64	91.9	68
Black	8.1	6	4.1	3
Hispanic	4.1	3	4.1	3
Asian	1.4	1	~	~
Religious Preference				
Catholic	6.8	5	4.1	3
Protestant	73	54	75.7	56
Jewish	2.7	2	2.7	2
Other	12	16.2	11	14.9
Current Health Status				
Poor	2.7	2	N/A	N/A
Fair	21.6	16	N/A	N/A
Good	55.4	41	N/A	N/A
Excellent	20.3	15	N/A	N/A

Table 3

SUMMARY OF TYPE OF ADVANCE DIRECTIVES, REALTIONSHIP TO PROXY, AND CHARACTERISTICS OF COMMUNICATION

Variable	<u>With AD</u> (n=52)		<u>Without AD</u> (n=22)	
	N	%	N	%
Type of AD				
Living Will	11	21.5	~	~
Power of Attorney	1	1.9	~	~
Both	40	76.9	~	~
Relation to Proxy				
Spouse	39	75	11	50
Family Member	13	25	4	18.1
Friend	1	1.9	~	~
No Response	~	~	7	31.8
Had discussions with:				
Proxy	12	23.1	3	13.6
Spouse	31	59.6	16	72.7
Children	7	13.4	2	9.1
No Response	2	3.8	1	4.5
Level of discussion				
Causal	4	7.7	11	50
General	11	21.5	1	4.5
Purposeful	14	26.9	7	31.8
In-depth/specific	21	40.3	2	9.1
No Response	2	3.8	1	4.5
How often discussed				
Never	1	1.9	~	~
Once	11	21.5	~	~
2-5 times	25	48.1	18	81.8
6-10 times	6	11.5	2	9.1
>10 times	7	13.4	1	4.5
No Response	2	3.8	1	4.5

Statistical Analysis of Research Questions

Research question 1: How do the judgments of individuals with an AD compare with the substituted judgments of their designated proxy? The questionnaires of the individuals and their respective proxies were compared and scored according to percent of agreement. A summary of the scores for individuals with AD is presented in Table 4. Of the individuals with an AD (n=52), 38.4% (n=20) of the proxies were in agreement at least 80% of the time.

The degree of concordance in each scenario that occurred beyond that expected by chance was measured by kappa coefficient. Kappa coefficient ranges from 0 - 1 where 0 is chance agreement and 1 represents perfect agreement, >0.40 is required to conclude a moderate or greater degree of agreement exist beyond that expected due to chance alone (Fleiss, 1973). The directionality of discordance was determined using McNemar chi square analysis.

In Situation A, 13 proxies demonstrated complete agreement with those individuals with an AD, 15 disagreed on 1-2 treatments, 19 disagreed on 3-5 treatments, 3 disagreed on 6-8 treatments, and 2 were in complete disagreement. Agreement of desired treatment and the discrepant responses are summarized in Table 5. Agreement between the individuals and their respective proxies was no greater than it would have been if left to chance.

In Situation B, 10 proxies demonstrated complete agreement with those individuals with an AD, 17 disagreed on 1-2 treatments, 18 disagreed on 3-5 treatments, 8 disagreed on 6-8 treatments, and 1 were in complete disagreement. Agreement of desired treatment and the discrepant responses are summarized in Table 6. No significance was noted for the degree of agreement in any of the treatments. Nutrition via tube or IV placement was the only treatment

Table 4

SUMMARY OF SCORES FOR INDIVIDUALS WITH AD

(n=52)	Situation A	Situation B	Situation C	Situation D	Overall %
101	77	100	100	88	92
103	77	88	66	77	78
104	77	100	100	100	94
105	44	55	77	44	56
108	88	88	77	88	86
109	100	44	77	77	75
110	66	88	100	66	81
111	100	77	66	77	81
112	66	66	33	55	56
113	66	88	88	77	81
114	0	0	66	44	28
115	100	100	33	33	67
116	88	88	100	66	86
117	0	11	33	77	31
118	100	33	33	22	47
119	88	88	88	66	83
120	88	88	77	77	83
121	88	100	100	100	97
122	100	100	100	100	100
123	100	100	100	100	100
124	100	100	100	100	100
130	100	55	100	55	78
134	100	100	100	100	100
140	77	66	88	66	75
141	66	11	33	44	39
142	66	66	66	66	67
144	77	77	88	88	83
145	11	11	88	33	36
151	33	66	77	66	61
152	55	55	66	77	64
153	100	100	88	88	94
154	66	22	77	100	67
156	100	77	77	100	89
157	66	66	66	66	67
158	66	88	88	66	78
159	66	77	77	77	75
227	88	100	44	88	81
228	88	77	55	44	67
236	55	55	44	66	56
237	88	44	44	55	56
243	55	77	22	55	53
246	100	55	77	88	81
268	100	100	88	100	97
270	66	33	33	66	50
271	55	44	66	66	58
272	88	22	22	22	39
274	77	66	55	55	64
275	55	44	66	66	58
276	66	77	77	66	72
277	33	22	66	88	53
280	66	66	66	55	64
281	55	88	77	66	72

Table 5

SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR SITUATION A

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	Direction of Discrepant Responses		McNemar Test	p
					Individual wants but proxy withheld	Individual did not want but proxy provided		
CPR	43	-0.09	[-0.16, -0.03]	9	4	5	0.11	0.74
Maj Surgery	44	0.34	[-0.01, 0.70]	8	3	5	0.50	0.48
Ventilator	37	-0.04	[-0.27, 0.20]	15	5	10	1.67	0.20
Dialysis	39	0.09	[-0.21, 0.39]	13	2	2	0.69	0.41
Blood Prod	40	0.29	[-0.03, 0.61]	11	6	5	0.09	0.76
Nutrition	33	0.05	[-0.22, 0.33]	19	8	11	0.47	0.49
Minor Proc	32	0.21	[-0.06, 0.47]	20	8	12	0.80	0.37
Antibiotics	30	0.18	[-0.8, 0.45]	21	8	13	1.19	0.28
Pain Meds	44	0.35	[0.00, 0.69]	8	2	6	2.00	0.16

Table 6

SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR
SITUATION B

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	Direction of Discrepant Responses		McNemar Test	p
					Individual wants but proxy withheld	Individual did not want but proxy provided		
CPR	37	-0.05	[-0.29, 0.19]	15	6	9	0.60	0.44
Maj Surgery	44	0.34	[-0.02, 0.70]	8	4	4	0.00	1.00
Ventilator	31	-0.08	[-0.31, 0.16]	21	7	14	2.33	0.13
Dialysis	35	-0.06	[-0.28, 0.15]	17	5	12	2.88	0.09
Blood Prod	37	0.35	[0.07, 0.63]	13	4	9	1.92	0.17
Nutrition	29	0.08	[-0.17, 0.33]	23	6	17	5.26	0.02
Minor Proc	31	0.19	[-0.08, 0.45]	21	9	12	0.43	0.51
Antibiotics	31	0.18	[-0.09, 0.44]	21	8	13	1.19	0.28
Pain Meds	41	0.14	[-0.18, 0.47]	11	5	6	0.09	0.76

to demonstrate a significance in the direction of discrepant responses. In 17 of the 23 discrepant responses, the proxy opted for nutrition by artificial means when the individual chose not to want it.

In Situation C, 10 proxies demonstrated complete agreement with those individuals with an AD, 20 disagreed on 1-2 treatments, 15 disagreed on 3-5 treatments, and 8 disagreed on 6-8 treatments. Agreement of desired treatment and the discrepant responses are summarized in Table 7. No significance was noted for the level of agreement. Major Surgery was the only treatment that showed a significant direction of discrepant responses. Of the 8 discrepant responses, all proxies opted to have major surgery performed while the individuals stated they would reject treatment. This is the only incidence in which the direction of discrepancy is significant for the withholding of desired treatment.

In Situation D, 9 proxies demonstrated complete agreement with those individuals with an AD, 15 disagreed on 1-2 treatments, 24 disagreed on 3-5 treatments, and 4 disagreed on 6-8 treatments. Agreement of desired treatment and the discrepant responses are summarized in Table 8. Agreement on treatments was equivalent of that due to chance alone, but the treatments, minor procedures and the administration of antibiotics, showed a significant direction of discrepancy. For minor procedures, of the 24 discrepant responses, 18 indicated the proxy would allow the performance of minor procedures that may be requested by the physician. Regarding the administration of antibiotics, 17 of 23 discrepant responses were to administer antibiotics if needed.

Table 7

SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR
SITUATION C

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	Direction of Discrepant Responses		McNemar Test	p
					Individual wants but proxy withheld	Individual did not want but proxy provided		
CPR	44	0.12	[-0.24, 0.47]	8	4	4	0.00	1.00
Maj Surgery	44	0.17	[-0.12, 0.47]	8	8	0	8.00	0.05
Ventilator	34	0.03	[-0.25, 0.30]	18	8	10	0.22	0.64
Dialysis	38	0.14	[-0.17, 0.44]	14	8	6	0.29	0.60
Blood Prod	37	0.27	[-0.03, 0.57]	13	7	6	0.08	0.78
Nutrition	34	0.19	[-0.08, 0.47]	18	7	11	0.89	0.35
Minor Proc	33	0.27	[0.01, 0.53]	19	10	9	0.05	0.82
Antibiotics [^]	29	0.13	[-0.14, 0.39]	22	9	13	0.73	0.39
Pain Meds	39	-0.01	[-0.28, 0.25]	13	6	7	0.08	0.78

[^]Missing one frequency

Table 8

SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR
SITUATION D

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	Direction of Discrepant Responses		McNemar Test	p
					Individual wants but proxy withheld	Individual did not want but proxy provided		
CPR	45	-0.06	[-0.12, 0.00]	7	2	5	1.29	0.26
Maj Surgery	41	-0.09	[-0.17, -0.14]	11	3	8	1.60	0.21
Ventilator	39	-0.01	[-0.27, 0.26]	13	5	8	0.69	0.41
Dialysis	40	0.12	[-0.20, 0.43]	12	7	5	0.33	0.56
Blood Prod	39	0.32	[0.04, 0.61]	13	4	9	1.92	0.17
Nutrition	34	0.18	[-0.10, 0.46]	18	8	10	0.22	0.64
Minor Proc	28	0.03	[-0.22, 0.28]	24	8	16	3.85	0.05
Antibiotics	29	0.13	[-0.12, 0.37]	23	6	17	5.26	0.02
Pain Meds	40	0.01	[-0.26, 0.29]	12	5	7	0.33	0.56

Research question 2: Are the substituted judgments of the proxies of individuals with an AD more accurate than the substituted judgments of proxies of individuals without an AD? The questionnaires of the individuals without an AD and their respective proxies were compared and scored according to percent of agreement. Once again the degree of concordance was determined by kappa coefficients and the directionality of discordance by McNemar chi-square. A summary of the scores for individuals without an AD is presented in Table 9. Of the individuals without an AD (n=22), 36.4% (n=8) demonstrated agreement greater than 80%. See Table 10 for a summary of a comparison of percentage scores against those of the group with AD.

In Situation A, 6 proxies demonstrated complete agreement with those individuals with an AD, 7 disagreed on 1-2 treatments, 5 disagreed on 3-5 treatments, and 4 disagreed on 6 treatments. Agreement of desired treatment and the discrepant responses are summarized in Table 11. A significant degree of agreement was noted for the treatments, CPR, ventilation, and use of antibiotics. No significance was noted for direction of discordance.

In Situation B, 6 proxies demonstrated complete agreement with those individuals with an AD, 5 disagreed on 1-2 treatments, 3 disagreed on 3-5 treatments, and 8 disagreed on 6-8 treatments. Agreement of desired treatment and the discrepant responses are summarized in Table 12. No significance was noted in the level of agreement or direction of discordance.

In Situation C, 5 proxies demonstrated complete agreement with those individuals with an AD, 3 disagreed on 1-2 treatments, 8 disagreed on 3-5 treatments, and 6 disagreed on 6-8 treatments. Agreement of desired treatment and the discrepant responses are summarized in Table 13. There was significant agreement for the administration of blood products only. No significance was noted for direction of discordance.

Table 9

SUMMARY OF PERCENTAGES FOR INDIVIDUALS WITHOUT AN AD

w/o AD (n=22)	Situation A	Situation B	Situation C	Situation D	Overall %
102	55	77	88	100	81
106	88	11	100	77	69
107	100	77	33	66	69
150	66	11	66	77	56
225	33	44	33	55	42
226	33	33	44	33	36
229	33	100	66	66	67
231	33	66	44	77	56
238	55	33	88	55	58
239	44	11	88	44	47
247	77	33	11	11	33
248	100	100	33	100	83
249	66	22	44	100	58
261	88	22	11	100	56
269	100	100	100	100	100
273	100	77	22	22	56
282	100	66	100	66	83
283	88	88	100	88	92
286	100	100	66	66	83
287	88	77	66	44	69
288	88	100	66	77	83
289	88	88	100	44	81

Table 10

COMPARISON OF PERCENTAGE SCORES OVER THE FOUR SCENARIOS FOR
GROUPS WITH AND WITHOUT ADVANCE DIRECTIVES

% Agreement	With AD (n=52)	Without AD (n=22)
100%	4	1
>80%	16	7
58-80%	19	7
<58%	13	7

Table 11
SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR INDIVIDUALS
WITHOUT AD FOR SITUATION A

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	Direction of Discrepant Responses		McNemar Test	p
					Individual wants but proxy withheld	Individual did not want but proxy provided		
CPR	18	0.48	[0.05, 0.92]	4	2	2	0.00	1.00
Maj Surgery	18	0.40	[-0.07, 0.87]	3	1	3	1.00	0.32
Ventilator	18	0.48	[0.05, 0.92]	4	2	2	0.00	1.00
Dialysis	15	0.24	[-0.19, 0.69]	7	3	4	0.14	0.71
Blood Prod	15	0.15	[-0.29, 0.60]	7	3	4	0.14	0.71
Nutrition	15	0.35	[-0.04, 0.75]	7	3	4	0.14	0.71
Minor Proc	16	0.44	[0.07, 0.81]	6	2	4	0.67	0.41
Antibiotics	16	0.46	[0.11, 0.80]	6	1	5	2.67	0.10
Pain Meds	16	0.32	[-0.11, 0.74]	6	2	4	0.67	0.32

Table 12

SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR INDIVIDUALS
WITHOUT AD FOR SITUATION B

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	<u>Direction of Discrepant Responses</u>		McNemar Test	p
					Individual wants but proxy withheld	Individual did not want but proxy provided		
CPR	12	0.09	[-0.32, 0.50]	10	4	6	0.40	0.53
Maj Surgery	14	0.21	[-0.20, 0.63]	8	4	4	0.00	1
Ventilator	12	0.18	[-0.19, 0.55]	9	2	7	2.78	0.1
Dialysis	11	0.05	[-0.33, 0.42]	11	3	8	2.27	0.13
Blood Prod	13	0.24	[-0.16, 0.65]	8	3	5	0.50	0.48
Nutrition	11	-0.03	[-0.43, 0.37]	11	4	7	0.82	0.37
Minor Proc	15	0.28	[-0.09, 0.65]	7	1	6	3.57	0.6
Antibiotics	15	0.21	[-0.17, 0.58]	7	1	6	3.57	0.06
Pain Meds	17	0.40	[-0.04, 0.83]	5	2	3	0.20	0.66

Table 13

SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR INDIVIDUALS WITHOUT AD FOR SITUATION C

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	<u>Direction of Discrepant Responses</u>		McNemar Test	p
					Individual wanted but proxy withheld	Individual did not want but proxy provided		
CPR	13	0.09	[-0.33, 0.51]	9	4	5	0.11	0.74
Maj Surgery	17	0.32	[-0.12, 0.76]	5	1	4	1.80	0.18
Ventilator	12	0.07	[-0.34, 0.48]	10	4	6	0.40	0.53
Dialysis	10	-0.14	[-0.51, 0.24]	12	4	8	1.33	0.25
Blood Prod	17	0.46	[0.05, 0.86]	5	2	3	0.20	0.66
Nutrition	12	0.11	[-0.27, 0.50]	10	3	7	1.60	0.21
Minor Proc	12	-0.04	[-0.44, 0.37]	10	4	6	0.40	0.53
Antibiotics	15	0.25	[-0.16, 0.66]	7	2	5	1.29	0.26
Pain Meds	16	0.10	[-0.35, 0.54]	6	2	4	0.67	0.41

In Situation D, 5 proxies demonstrated complete agreement with those individuals with an AD, 5 disagreed on 1-2 treatments, 9 disagreed on 3-5 treatments, and 3 disagreed on 6-8 treatments. Agreement of desired treatment and the discrepant responses are summarized in Table 14. There was a strong level of agreement for the performance of minor procedures and for the administration of antibiotics. There was no significance in the direction of discordance.

The agreement of proxies and individuals with an AD was compared to the agreement of proxies and individuals without an AD for each scenario, treatments within that scenario, and agreement over the four scenarios. See Table 15 for the mean scores, standard deviations, and t-tests for the two groups for each scenario and a composite score of the four scenarios. Although the group with AD scored consistently higher than the group without AD, t-tests did not reveal a significance in the difference of the scores.

Odds ratios were examined for a composite of the four scenarios, each scenario, and each treatment within that scenario. See Table 16 for an over view of the odds ratio. For each scenario, the likelihood of agreement between an individual and their proxy is no better than chance regardless of the presence of an AD. However, scenario specific treatments do have significantly greater odds of agreement when an AD is present. Cardiopulmonary resuscitation, major surgery, dialysis, and pain medications are treatments that have greater odds of agreement over all four scenarios with an AD. Minor procedures and antibiotics have no better than chance of agreement across the scenarios. Use of a ventilator for respiratory support, administration of blood products, and nutrition varied in significance depending on the

Table 14

SUMMARY OF AGREEMENT AND DISCREPANT RESPONSES FOR INDIVIDUALS WITHOUT AD FOR SITUATION D

Treatments	# in Agreement	kappa coefficient	Confidence Bounds	Discrepant responses	Direction of Discrepant Responses		McNemar Test	p
					Individual wanted but proxy withheld	Individual did not want but proxy provided		
CPR [^]	17	0.38	[-0.11, 0.88]	5	2	3	0.00	1.00
Maj Surgery [^]	11	0.31	[-0.12, 0.74]	11	4	7	0.67	0.41
Ventilator [^]	14	0.20	[-0.18, 0.57]	8	1	7	3.57	0.06
Dialysis ^{^^}	13	0.06	[-0.38, 0.49]	9	3	6	0.50	0.48
Blood Prod [^]	16	0.22	[-0.23, 0.67]	6	2	4	0.67	0.41
Nutrition [^]	10	-0.07	[-0.47, 0.34]	12	4	8	0.82	0.37
Minor Proc [^]	17	0.6	[0.26, 0.94]	5	1	4	1.00	0.32
Antibiotics [^]	17	0.54	[0.15, 0.93]	5	1	4	1.00	0.32
Pain Meds [^]	16	0.22	[-0.21, 0.66]	6	2	4	0.41	0.71

[^]Missing one frequency^{^^}Missing two frequencies

Table 15

SUMMARY OF THE MEAN SCORES, STANDARD DEVIATIONS, AND T-TESTS OF EACH SCENARIO AND OVER THE FOUR SCENARIOS FOR GROUPS WITH AND WITHOUT ADVANCE DIRECTIVES

Scenario	<u>With AD</u> (n=52)		<u>Without AD</u> (n=22)		<u>t-test results</u>		
	Mean Score	sd	Mean Score	sd	t value	df	2-tail p
Overall	25.42	6.86	23.73	6.65	0.98	72	0.33
Situation A	6.58	2.29	6.68	2.30	-0.18	72	0.86
Situation B	6.08	2.57	5.45	2.99	0.91	72	0.37
Situation C	6.38	2.12	5.64	2.75	1.27	72	0.21
Situation D	6.38	1.88	5.95	2.50	0.81	72	0.42

Table 16

SUMMARY OF ODDS RATIO FOR SCENARIOS AND SCENARIO SPECIFIC TREATMENT

Scenario	# With AD (n=52)	# Without AD (n=22)		Confidence
Treatments	Agreement	Agreement	Odds Ratio	Bounds
Overall	4	1	1.76	[0.19, 16.71]
Situation A	13	6	0.94	[0.30, 2.93]
CPR	43	18	1.06	[0.29, 3.90]
Maj Surgery	44	18	1.22	[0.33, 4.57]
Ventilator	37	18	0.55	[0.16, 1.89]
Dialysis	39	15	1.40	[0.47, 4.19]
Blood Prod	40	15	1.70	[0.56, 5.19]
Nutrition	33	15	0.81	[0.28, 2.34]
Minor Proc	32	16	0.60	[0.20, 1.79]
Antibiotics	30	16	0.54	[0.18, 1.60]
Pain Meds	44	16	2.06	[0.62, 6.87]
Situation B	11	5	0.85	[0.25, 2.85]
CPR	37	12	2.06	[0.73, 5.76]
Maj Surgery	44	14	3.14	[1.02, 9.71]
Ventilator	31	12	1.11	[0.39, 3.11]
Dialysis	35	11	2.06	[0.75, 5.68]
Blood Prod	37	13	1.75	[0.59, 5.19]
Nutrition	29	11	1.26	[0.46, 3.44]
Minor Proc	31	15	0.69	[0.24, 1.99]
Antibiotics	31	15	0.69	[0.34, 1.99]
Pain Meds	41	17	1.10	[0.33, 3.66]
Situation C[^]	10	5	0.87	[0.26, 2.96]
CPR	44	13	3.81	[1.26, 11.51]
Maj Surgery	44	17	1.62	[0.46, 5.65]
Ventilator	34	12	1.57	[0.57, 4.36]
**Dialysis	38	10	3.26	[1.17, 9.07]
Blood Prod	37	17	0.84	[0.26, 2.75]
Nutrition	34	12	1.57	[0.57, 4.36]
Minor Proc	33	12	1.45	[0.52, 4.00]
*Antibiotics	29	15	0.62	[0.21, 1.77]
Pain Meds	39	16	1.13	[0.36, 3.50]
Situation D^{^^}	9	5	0.66	[0.19, 2.29]
*CPR	45	17	1.51	[0.39, 5.85]
**Maj Surgery	41	15	1.64	[0.51, 5.31]
*Ventilator	39	14	1.50	[0.50, 4.54]
**Dialysis	40	12	2.22	[0.74, 6.66]
*Blood Prod	39	15	1.20	[0.39, 3.74]
**Nutrition	33	10	2.02	[0.72, 5.65]
*Minor Proc	26	17	0.24	[0.07, 0.76]
*Antibiotics	29	17	0.30	[0.09, 1.00]
Pain Meds	40	14	1.67	[0.55, 5.08]

[^]Missing 3 frequencies

*Missing 1 frequency

^{^^}Missing 4 frequencies

**Missing 2 frequencies

scenario. For agreement over the four scales the odds for agreement was greater if one had an AD.

Additional Findings

Data were collected from individuals regarding their perception of how often they had communicated their wishes to their proxy (HD) and at what level these discussions took place (LD). A general linear model was used to analyze the variance of the factors of LD and HD separately in the two groups to determine if the reported level of discussion (LD) and/or how often (HD) these discussions took place had any effect on the agreement between an individual and proxy. Table 17 provides the F values for the variables of LD and HD for the four scenarios as it applies to each groups. There were no significant findings for the group without AD for either the level of discussion or how often discussions took place. For the group with AD, there was a weak significance related to how often discussions took place for Situation C and over all the four scenarios. There was a strong significance related to the number of discussions in Situation D. Situation A was the only scenario to have increased agreement related to the level of discussions.

Summary. This chapter presented the results of the study based on the research questions. For the group with AD, no significance was noted for the level of agreement for any of the scenarios between an individual and proxy. In comparison to the group without an AD, there was a greater chance of agreement if an AD was present. The level of discussion appears to have little effect on concordance except those with AD discussing issues related to Situation A, an irreversible coma with no known chance of recovery. How often discussions take place does appear to have an impact on agreement for those with an AD, especially regarding issues associated with Situation D, irreversible brain disease such as dementia.

Table 18

ANOVA FOR COMPARISON OF LEVEL AND NUMBER OF DISCUSSIONS WITH
LEVEL OF AGREEMENT FOR GROUPS WITH AND WITHOUT AD

Scenario	With AD	Without AD
Overall		
LD	F=1.96(3,46) p=0.133	F=0.15(3,17) p=0.930
HD	F=2.27(4, 45) p=0.076	F=0.69(2,18) p=0.516
Situation A		
LD	F=3.42(3, 46) p=0.025	F=0.86(3, 17) p=0.483
HD	F=1.50(4,45) p=0.217	F=0.66(2, 18) p=0.531
Situation B		
LD	F=1.91(3,46) p=0.141	F=0.14(3,17) p=0.936
HD	F=2.09(4, 45) p=0.098	F=1.44(2, 18) p=0.263
Situation C		
LD	F=1.08(3, 46) p=0.366	F=0.41(3, 17) p=0.751
HD	F=2.44(4,45) p=0.060	F=0.42(2,18) p=0.664
Situation D		
LD	F=0.41(3, 46) p=0.748	F=0.60(3, 17) p=0.625
HD	F=3.74(4, 45) p=0.010	F=0.91(2, 18) p=0.418
LD=level of discussion		
HD=number of discussions		

Chapter V

DISCUSSION

The purpose of this study was to examine and compare individuals' perceived end-of-life choices to those of the person acting as their proxy in the event they are no longer able to make decisions for themselves. The research questions were:

1. How do the judgments of individuals with an AD compare with the substituted judgments of their designated proxy?
2. Are the substituted judgments of the proxies of individuals with an AD more accurate than the substituted judgments of proxies of individuals without an AD?

The literature reflects only a 59-80% accuracy of substituted judgments for hypothetical situations and cites inadequate communication as the probable cause for the inaccuracy (Secker, Meier, Mulvihill, & Cammer Paris, 1991; Ouslander, Tymchuk, & Rahbar, 1989; Hare, Pratt, & Nelson, 1992; and Sulmasy, Haller, & Terry, 1994). These previous studies did not directly address the presence of an AD as a factor that may influence the accuracy of these judgments. This study investigated the accuracy of the substituted judgments made by the proxies of individuals with an AD and how they might compare with the accuracy of proxies chosen by individuals who did not have an AD.

This study used scenarios from the Medical Directive developed by Emanuel and Emanuel (1989). A list of treatments is given for each of four scenarios. The individual could choose to reject or accept the treatment. The proxy would base acceptance or rejection of the treatment based on what he felt the individual appointing him would choose. The sample consisted of individuals 54 years and older solicited from two Air Force retirement

communities in San Antonio, Texas, and the community of Seguin, Texas. Participation was voluntary and participants were assured of anonymity.

The population was divided into two groups, those with an AD and those without AD. Analysis included using kappa coefficients and McNemar Test to compare the responses of the individuals to their respective proxies. No significance in concordance was noted for the group with AD (kappa ≥ 0.35 , percent agreement range, 31%-100%). The group without AD, however, did have significant concordance for specific treatments in Situation A, C, and D (kappa ≥ 0.40 , percent agreement range, 33%-100%). T-tests and Odd's Ratios were used to compare the two groups' concordance level. Overall there was not a significant difference in the agreement of the two groups, although there was a slightly greater chance of agreement if an AD was present. ANOVA was used to determine if the level of discussion surrounding end-of-life issues and how often these discussion were held made an impact on the agreement between individual and proxy. The level of discussion was only significant for Situation A for the group with AD. The number of discussions was strongly significant for the concordance within the group with AD for Situation D and slightly significant overall and for Situation C.

Findings from this study do not demonstrate a statistically significant level of concordance of the substituted judgments of proxies for individuals with or without an AD and reflects the current literature. It does, however, demonstrate that the presence of an AD may increase the chance of agreement between the individual and proxy. Since the number and level of discussions for certain situations did reflect greater agreement, the AD may serve as an initiator and guide for communication.

In order for proxies to know what individuals appointing them would do in any given situation, those individuals must communicate what is expected. The decisions the proxy must make should ideally reflect those of the individual appointing the proxy. Direct communication by the individual to the proxy would be the most efficient method of dispersing this information to the proxy, but this is not always the case. The person most commonly appointed as a proxy is a family member, the spouse, a child or other relative. Talking about death and dying is rarely easy for anyone. It may be difficult for the individual to initiate and it may be as difficult if not more so for the proxy to hear. The difficulty of imparting or receiving the information can interfere with the relevance of the information for the listener and decrease the congruity of thought in regards to end-of-life decisionmaking.

This is reflected when examining the scores across the four scenarios. The degree of accuracy often fluctuated from one scenario to the next. A proxy may be in complete agreement for Situation A, but then drop to less than 50% concordance in Situation B or show low concordance for Situation A and B, but have complete agreement for Situation D. The fluctuations may be due to several factors. Since each situation reflected a different scenario, some situations may be easier to discuss. A situation that offers no hope of recovery leaves little room for feelings of guilt for withholding potentially beneficial treatments. Yet when there is a chance of recovery or no obvious physical illness, the decisions may be harder to make. Another factor may be life experiences of those involved. Having a family member or close friend experience a situation as described by the scenarios may precipitate communication regarding what one could expect and may or may not want under those circumstances. Such experience may facilitate receptiveness by the proxy to such information.

In Situation A, the scenario depicting an irreversible coma with no chance of recovery, one might assume there would be high concordance due to the implied lack of hope. Of the 74 individuals, 47% had an agreement of 88% or better. Interestingly, the group without AD had significant concordance on five of the nine treatments, while the group with AD demonstrated no significant agreement. There was no significant difference in the level of agreement between the two groups. However, when comparing the two groups, the chance of agreement was significantly improved with the level of discussion for the group with AD. This implies a couple of things. This situation is one that does not present many options for care, does not present any ethical dilemmas for the individual or proxy, and does not require extensive communication regarding outcomes.

Situation B, on the other hand, showed a lower level of concordance. Thirty-six percent demonstrated an agreement of 88% or more. In 13 of the 74, there was an increase of 2-7 discrepant responses. This scenario presents a small chance for recovery. The direction of discrepant responses were consistently to chose to accept treatments the individual did not want, especially nutrition ($p=0.022$). This situation may raise ethical questions for both the individual and the proxy because of the chance of recovery. Personal values, religious beliefs, emotional or financial dependence on the person may be just a few of the factors interfering with discussions and judgments for such a scenario. Knowledge of what constitutes “a small chance” of recovery may influence discussion and judgment as well. The lack of a clear picture makes it a difficult scenario to discuss, especially for those with little or no knowledge of health care and disease processes.

Situation C, like Situation A, presents a clearer picture. This scenario is one of terminal illness with weeks to live. It also presents a situation with little hope, yet only 35% demonstrated an agreement of 88% or greater. For nine individuals, their proxy showed the greatest agreement for this scenario over the other three. For this situation the direction of discrepant responses was mixed. Although not statistically significant, the group without AD the proxies were consistent in providing unwanted treatment for the individuals. For those with AD, there was a significant withholding of major surgery by the proxy of individuals who chose to accept the treatment ($p=0.005$). Other treatments in which the trend was for the proxy to reject treatment desired by the individuals, though not statistically significant, were dialysis, the administration of blood products, and the performance of minor procedures. These inconsistencies may reflect mixed messages in the communication of individuals with AD. Often discussions regarding AD are general and not directed toward specific disease states. An individual may make a general statement such as, he does not want any extraneous measures be taken to prolong life. There is no elaboration on what extraneous measures are or in what situations these measures may take place. Terminal illness may present a different picture dependent on what experience one has with it. A proxy may wish to avoid pain and suffering, while the individual wants to fight the disease as long as possible. The hope for a cure, the need to fulfill a short term goal, or denial of the disease itself. The need for direct communication regarding what one wants "in the event of" is evident.

Situation D, depicting a brain disease such as dementia, had the lowest degree of concordance. Only 30% demonstrated an agreement of 88% or greater. Five pairs were in complete agreement for this scenario only and six others, while not in complete agreement,

scored highest in this scenario. There was a significant degree of agreement for the group without AD regarding performance of minor procedures and the administration of antibiotics. The general direction of discrepant responses was for the proxy to accept treatment the individual would have rejected. In the group with AD, this was significant for minor procedures ($p=0.05$) and antibiotics ($p=0.022$). This scenario is a difficult situation for most individuals. The body may be fairly healthy while the mind is not. Families or individuals without experience of such situations often have no idea what to expect or what to plan for. With or without personal experience, discussions surrounding the issues of this scenario are difficult as the disease process is difficult to predict.

An unexpected finding during the collection of the data was the difficulty of finding individuals in this age group without an AD document. There are several possible factors that may contribute to this. Enforcement and revisions of the Patient Self-Determination Act may have influenced hospitals and physicians to at least present the option for an advance directive to patients, if not provide services to obtain one. Exposure to the health care system may also influence one's decision to obtain an AD. This age population has more than likely dealt with the death of their parents and possibly a spouse or child. Also this population may have declining health or chronic health problems requiring frequent physician or hospital visits. The sample solicited from Air Force Village was provided with information and counseling regarding advance directives upon becoming a resident. In the sample for this study, of the 22 without AD, 11 acknowledged the need and desire for an AD, but "had not gotten around to it."

Implications for Nursing. Nurses have a legitimate concern for maintaining the autonomy of the patient. Although the AD and use of a proxy has been heralded as maintaining that autonomy in the event of incapacitation, it has not necessarily done so if one is to use the standard of substituted judgment. The AD is a tool that can be used to assist in decision making for someone who is no longer able to make decisions and should be treated as such. Nurses need to be aware of the presence of AD documents and the designation of a proxy, if any. The AD can be used to facilitate discussions of desired health care with the physician, other nursing staff, and the family. Communication improves the chance of accurate substituted judgment by a proxy, but patients and families often do not know what issues they may face when a loved one becomes incapacitated. The multiple reasons for incapacitation further complicates effective communication. The nurse often has the best opportunities to facilitate and guide such discussions.

Limitations. There are several limitations to this study. The use of a convenience sample limited the characteristics to predominately Caucasian, married, college educated, and Protestant. This limits generalization.

No attempts were made to control for communication prior to the study. Data regarding the discussions between individuals and proxies was based on self report of the individuals only. No data were collected from the proxy regarding the number or level of discussions with the individual appointing them. Analysis may not truly reflect the impact of communication on the accuracy of substituted judgment.

No data were collected regarding the individual or proxy's knowledge of advance directives or the concept of substituted judgment. The advance directive documents of

participants were not reviewed. Often, a patient will complete a form because the doctor, or nurse, or administration person has instructed them to do so. Many AD are vague and of little value.

The hypothetical nature of the scenarios may have limited the accuracy of the responses. A questionnaire is void of the emotions, health care providers input, family support, as well as financial factors that influence one's decision making.

Recommendations for Future Research. There are many unanswered questions regarding the effectiveness of advance directives and the use of substituted judgment. This study and those cited in the literature review are primarily focused on an older, Caucasian population. Studies are needed that address other age groups and cultures.

Communication plays strongly in substituted judgment and should be examined more closely. A direct measure of communication should be incorporated into future studies. Evaluation of facilitated or guided discussions regarding end-of-life issues could be measured by using similar scenarios as a pre/posttest to measure for improvement in accuracy. A comparison of the individual's perception of the quality of communication to the proxy versus the proxy's perception of the quality of information received.

The concern surrounding the adherence to the standard of substituted judgment may be unwarranted. Determination of what the appropriate level of agreement for the general population warrants investigation. Is there a different level of concern on how accurate a proxy is when a treatment is less invasive, such as x-rays or maintenance doses of medications, than more invasive, life prolonging procedures, such as CPR or major surgery.

The Medical Directive

Introduction. As part of a person's right to self-determination, every adult may accept or refuse any recommended medical treatment. This is relatively easy when people are well and can speak. Unfortunately, during serious illness they are often unconscious or otherwise unable to communicate their wishes — at the very time when many critical decisions need to be made.

The Medical Directive allows you to record your wishes regarding various types of medical treatments in several representative situations so that your desires can be respected. It also lets you appoint a proxy, someone to make medical decisions in your place if you should become unable to make them on your own.

The Medical Directive comes into effect only if you become incompetent (unable to make decisions and too sick to have wishes). You can change it at any time until then. As long as you are competent, you should discuss your care directly with your physician.

Completing the form. You should, if possible complete the form in the context of a discussion with your physician. Ideally, this should occur in the presence of your proxy. This lets your physician and your proxy know how you think about these decisions, and it provides you and your physician with the opportunity to give or clarify relevant personal or medical information. You may also wish to discuss the issues with your family, friends, or religious mentor.

The Medical Directive contains six illness situations that include incompetence. For each one, you consider possible interventions and goals of medical care. Situation A is permanent coma; B is near death; C is with weeks to live in and out of consciousness; D is extreme dementia; E is a situation you describe; and F is temporary inability to make decisions.

For each scenario you identify your general goals for care and specific intervention choices. The interventions are divided into six groups: 1) cardiopulmonary resuscitation or major surgery; 2) mechanical breathing or dialysis; 3) blood transfusions or blood products; 4) artificial nutrition and hydration; 5) simple diagnostic tests or antibiotics; and 6) pain medications, even if they dull consciousness and indirectly shorten life. Most of these treatments are described briefly. If you have further questions, consult your physician.

Your wishes for treatment options (I want this treatment; I want this treatment tried, but stopped if there is no clear improvement; I am undecided; I do not want this treatment) should be indicated. If you choose a trial of treatment, you should understand that

this indicates you want the treatment *withdrawn* if your physician and proxy believe that it has become futile.

The Personal Statement section allows you to explain your choices, and say anything you wish to those who may make decisions for you concerning the limits of your life and the goals of intervention. For example, in situation B, if you wish to define "uncertain chance" with numerical probability, you may do so here.

Next you may express your preferences concerning organ donation. Do you wish to donate your body or some or all of your organs after your death? If so, for what purpose(s) and to which physician or institution? If not, this should also be indicated in the appropriate box.

In the final section you may designate one or more proxies, who would be asked to make choices under circumstances in which your wishes are unclear. You can indicate whether or not the decisions of the proxy should override your wishes if there are differences. And, should you name more than one proxy, you can state who is to have the final say if there is disagreement. Your proxy must understand that this role usually involves making judgments that you would have made for yourself, had you been able — and making them by the criteria you have outlined. Proxy decisions should ideally be made in discussion with your family, friends, and physician.

What to do with the form. Once you have completed the form, you and two adult witnesses (other than your proxy) who have no interest in your estate need to sign and date it.

Many states have legislation covering documents of this sort. To determine the laws in your state, you should call the state attorney general's office or consult a lawyer. If your state has a statutory document, you may wish to use the Medical Directive and append it to this form.

You should give a copy of the completed document to your physician. His or her signature is desirable but not mandatory. The Directive should be placed in your medical records and flagged so that anyone who might be involved in your care can be aware of its presence. Your proxy, a family member, and/or a friend should also have a copy. In addition, you may want to carry a wallet card noting that you have such a document and where it can be found.

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An earlier version of this form was originally published as part of an article by Linda L. Emanuel and Ezekiel J. Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document," *Journal of the American Medical Association* 261:3288-3293, June 9, 1989. It does not reflect the official policy of the American Medical Association.

MY PERSONAL STATEMENT

(Use back page if necessary)

Please mention anything that would be important for your physician and your proxy to know. In particular, try to answer the following questions: 1) What medical conditions, if any, would make living so unpleasant that you would want life-sustaining treatment *withheld*? (Intractable pain? Irreversible mental damage? Inability to share love? Dependence on others? Another condition you would regard as intolerable?) 2) Under what medical circumstances would you want to stop interventions that might already have been started? 3) Why do you choose what you choose?

If there is any difference between my preferences detailed in the illness situations and those understood from my goals or from my personal statement, I wish my treatment selections / my goals / my personal statement (*please delete as appropriate*) to be given greater weight.

When I am dying, I would like — if my proxy and my health-care team think it is reasonable — to be cared for:

- ☐ at home or in a hospice
- ☐ in a nursing home
- ☐ in a hospital
- ☐ other (*please specify*): _____

HEALTH CARE PROXY

I appoint as my proxy decision-maker(s):

Name and Address
and (optional)

Name and Address

I direct my proxy to make health-care decisions based on his/her assessment of my personal wishes. If my personal desires are unknown, my proxy is to make health-care decisions based on his/her best guess as to my wishes. My proxy shall have the authority to make all health-care decisions for me, including decisions about life-sustaining treatment, if I am unable to make them myself. My proxy's authority becomes effective if my attending physician determines in writing that I lack the capacity to make or to communicate health-care decisions. My proxy is then to have the same authority to make health-care decisions as I would if I had the capacity to make them, EXCEPT (list the limitations, if any, you wish to place on your proxy's authority):

I wish my written preference to be applied as exactly as possible / with flexibility according to my proxy's judgment. (Delete as appropriate)

Should there be any disagreement between the wishes I have indicated in this document and the decisions favored by my above-named proxy, I wish my proxy to have authority over my written statements / I wish my written statements to bind my proxy. (Delete as appropriate)

If I have appointed more than one proxy and there is disagreement between their wishes, _____ shall have final authority.

Signed: _____
Signature Printed Name

Address Date
Witness: _____
Signature Printed Name

Address Date
Witness: _____
Signature Printed Name

Address Date

Physician (optional):

I am _____'s physician. I have seen this advance care document and have had an opportunity to discuss his/her preferences regarding medical interventions at the end of life. If _____ becomes incompetent, I understand that it is my duty to interpret and implement the preferences contained in this document in order to fulfill his/her wishes.

Signed: _____
Signature Printed Name

Address Date

MY MEDICAL DIRECTIVE

This Medical Directive shall stand as a guide to my wishes regarding medical treatments in the event that illness should make me unable to communicate them directly. I make this Directive, being 18 years or more of age, of sound mind, and appreciating the consequences of my decisions.

SITUATION A

If I am in a coma or a persistent vegetative state and, in the opinion of my physician and two consultants, have no known hope of regaining awareness and higher mental functions no matter what is done, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only
- ☐ other (please specify): _____

Please check appropriate boxes:

1. **Cardiopulmonary resuscitation** (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying).

2. **Major surgery** (for example, removing the gallbladder or part of the colon).

3. **Mechanical breathing** (respiration by machine, through a tube in the throat).

4. **Dialysis** (cleaning the blood by machine or by fluid passed through the belly).

5. **Blood transfusions or blood products.**

6. **Artificial nutrition and hydration** (given through a tube in a vein or in the stomach).

7. **Simple diagnostic tests** (for example, blood tests or x-rays).

8. **Antibiotics** (drugs used to fight infection).

9. **Pain medications, even if they dull consciousness and indirectly shorten my life.**

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION B

If I am near death and in a coma and, in the opinion of my physician and two consultants, have a small but uncertain chance of regaining higher mental functions, a somewhat greater chance of surviving with permanent mental and physical disability, and a much greater chance of not recovering at all, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only
☐ other (please specify): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION C

If I have a terminal illness with weeks to live, and my mind is not working well enough to make decisions for myself, but I am sometimes awake and seem to have feelings, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

*In this state, prior wishes need to be balanced with a best guess about your current feelings. The proxy and physician have to make this judgment for you.

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only
☐ other (please specify): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION D

If I have brain damage or some brain disease that in the opinion of my physician and two consultants cannot be reversed and that makes me unable to think or have feelings, *but I have no terminal illness*, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only
☐ other (please specify): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION E

If I ...

(describe a situation that is important to you and/or your doctor believes you should consider in view of your current medical situation):

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only
☐ other (please specify): _____

I want	I want treatment tried. If no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

SITUATION F

If I am in my current state of health (describe briefly): _____

and then have an illness that, in the opinion of my physician and two consultants, is life threatening but reversible, and I am temporarily unable to make decisions, then my goals and specific wishes — if medically reasonable — would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only
- ☐ other (please specify): _____

I want	I want treatment tried if no clear improvement, stop.	I am undecided	I do not want
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		
	Not applicable		

Please check appropriate boxes:

1. **Cardiopulmonary resuscitation** (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying).
2. **Major surgery** (for example, removing the gallbladder or part of the colon).
3. **Mechanical breathing** (respiration by machine, through a tube in the throat).
4. **Dialysis** (cleaning the blood by machine or by fluid passed through the belly).
5. **Blood transfusions or blood products.**
6. **Artificial nutrition and hydration** (given through a tube in a vein or in the stomach).
7. **Simple diagnostic tests** (for example, blood tests or x-rays).
8. **Antibiotics** (drugs used to fight infection).
9. **Pain medications, even if they dull consciousness and indirectly shorten my life.**

ORGAN DONATION

—I hereby make this anatomical gift, to take effect after my death:

- I give ☐ my body
☐ any needed organs or parts
☐ the following parts _____
- to ☐ the following person or institution _____
☐ the physician in attendance at my death
☐ the hospital in which I die
☐ the following physician, hospital storage bank, or other medical institution:

- for ☐ any purpose authorized by law
☐ therapy of another person
☐ medical education
☐ transplantation
☐ research

—I do not wish to make any anatomical gift from my body.

Additional copies of the Medical
Directive may be obtained from:
The Medical Directive
P.O. Box 6100
Holliston, MA 01746-6100
1-800-214-4553

Situation A

If I am in a coma or in a persistent vegetative state and, in the opinion of my physician and two consultants, have no known hope of regaining awareness and higher mental functions no matter what is done, then my goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only

Please check appropriate boxes:

	I WANT	I DO NOT WANT	I WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>

Situation B

If I am near death and in a coma and, in the opinion of my physician and two consultants, have a small but uncertain chance of regaining higher mental functions, a somewhat greater chance of surviving with permanent mental and physical disability, and a much greater chance of not recovering at all, then my goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only

Please check appropriate boxes:

	I WANT	I DO NOT WANT	I WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>

Situation C

If I have a terminal illness with weeks to live, and my mind is not working well enough to make decisions for myself, but I am sometimes awake and seem to have feeling, then my goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only

Please check appropriate boxes:

	I WANT	I DO NOT WANT	I WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>

Situation D

If I have brain damage or some brain disease that in the opinion of my physician and two consultants cannot be reversed and that makes me unable to think or have feelings, *but I have no terminal illness*, then my goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only

Please check appropriate boxes:

	I WANT	I DO NOT WANT	I WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>

Situation A

If this person was in a coma or in a persistent vegetative state and, in the opinion of the physician and two consultants, has no known hope of regaining awareness and higher mental functions no matter what is done, then the goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only

Please check appropriate boxes:

	WANT	DO NOT WANT	WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>

Situation B

If this person was near death and in a coma and, in the opinion of the physician and two consultants, has a small but uncertain chance of regaining higher mental functions, a somewhat greater chance of surviving with permanent mental and physical disability, and a much greater chance of not recovering at all, then the goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only

Please check appropriate boxes:

	WANT	DO NOT WANT	WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>

Situation C

If this person has a terminal illness with weeks to live, and his/her mind is not working well enough to make decisions for him/herself, but he/she is sometimes awake and seem to have feelings, then the goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
☐ attempt to cure, but reevaluate often
☐ limit to less invasive and less burdensome interventions
☐ provide comfort care only

Please check appropriate boxes:

	WANT	DO NOT WANT	WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>

Situation D

If this person has brain damage or some brain disease that in the opinion of the physician and two consultants cannot be reversed and that makes him/her unable to think or have feelings, *but he/she has no terminal illness*, then the goals and specific wishes--if medically reasonable--for this and any additional illness would be:

- ☐ prolong life; treat everything
- ☐ attempt to cure, but reevaluate often
- ☐ limit to less invasive and less burdensome interventions
- ☐ provide comfort care only

Please check appropriate boxes:

	WANT	DO NOT WANT	WANT TREATMENT TRIED. IF NO CLEAR IMPROVEMENT, STOP
1. Cardiopulmonary resuscitation (chest compressions, drugs, electric shocks, and artificial breathing aimed at reviving a person who is on the point of dying)			<i>Not applicable</i>
2. Major surgery (for example, removing the gallbladder or part of the colon)			<i>Not applicable</i>
3. Mechanical Breathing (respiration by machine, through a tube in the throat)			
4. Dialysis (cleaning the blood by machine or by fluid passed through the belly)			
5. Blood transfusions or blood products			<i>Not applicable</i>
6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)			
7. Simple diagnostic tests (for example, blood tests or x-rays)			<i>Not applicable</i>
8. Antibiotics (drugs used to fight infection)			<i>Not applicable</i>
9. Pain medications, even if they dull consciousness and indirectly shorten my life			<i>Not applicable</i>



AFV I

The Villages



AFV II

17 June 1997

Captain Nina Watson
1734 Eastwood
Seguin, Texas 78155

Dear Captain Watson:

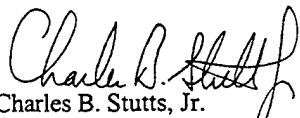
As we discussed yesterday, we would be happy for you to solicit volunteers from our residents to participate in your thesis research. We can see where the Power of Attorney and the advance directives may come in conflict. You can also solicit volunteers from our residents who may not have any advance directives if this helps your research.

Most of our single residents have Power of Attorneys who are outside the San Antonio regional area as we also discussed yesterday. However you will probably have enough responses to make the survey statistically significant.

We request that you brief our staff of the results when you have finished your study. I think we agreed that this will be no problem.

I will be your point of contact for obtaining the volunteers, scheduling meetings locations, etc. Good luck on your research.

Sincerely,


Charles B. Stutts, Jr.
Director of Resident Services

cc: Allan Perry, Dennis Alsup



June 30, 1997

Dr. Leslie Goddard
University of Texas Health Science Center
7703 Floyd Curl Drive
San Antonio, Texas 78284

Dear Dr. Goddard and Members of the Investigation Review Board;

Air Force Village II has agreed to assist Capt. Nina Watson with her thesis project pending your approval.

It was a pleasure to meet with her and to discuss her proposed thesis. The study to examine the congruence between expected end of life decisions of a person with an advance directive and the person they have named as a proxy decision maker could be beneficial to our residents, as well as to health care providers.

Air Force Village agrees to assist in soliciting volunteers by printing a request in our in-house newsletter and providing sign-up sheets in our facility. We agree to provide the space for interviews. We cannot guarantee the sufficient number of volunteers. We ask that the data collected remain confidential. Upon completion of study, we would appreciate a presentation for volunteers and staff to share results of the study.

If your approval is given, we will look forward to working with Capt. Watson.

Sincerely,

PEGGY W. SAWYER
Resident Counselor

PWS:pls



June 30, 1997

Captain Nina Watson
1734 Eastwood
Seguin, Texas 78155

Dear Captain Watson;

It was a pleasure to meet with you and discuss your proposed thesis work. The study to examine the congruence between expected end of life decisions of a person with an advance directive and the person they have named as a proxy decision maker should be revealing. The study could be beneficial to our residents, as well as the health care providers.

Air Force Village agrees to assist you, in soliciting volunteers by printing your request in our in-house newsletter and by providing sign-up sheets in our community rooms. We will provide a place for interviews. Air Force Village cannot guarantee the success in soliciting volunteers, but, we will provide assistance.

We ask that information remain confidential. Your plan to identify by number is excellent. We would also like an out-brief for staff and residents.

I look forward to hearing from you in mid-August to coordinate dates and data for beginning this project.

Sincerely,

PEGGY W. SAWYER
Resident Counselor

PWS;pls

Volunteers Needed for a Research Study

Capt. Nina Watson, an AFIT student at the UTHSCSA, is conducting a research study for her thesis as part of her Graduate Program. Her study is examining the similarity of healthcare choices made by a person and a substitute decisionmaker for that person. She will need volunteers who do and do not have advance directive documents and their respective substitute decisionmakers. The research study will involve completing a questionnaire and should take less than an hour of your time. If you would like to participate or have any questions, you may call Capt. Watson at 303-2631 or contact _____. A sign up list will be located _____.

SUBJECT CONSENT TO TAKE PART IN A STUDY OF
The Accuracy of a Proxy's Substituted Judgments for Individuals with and without Advance Directives
The University of Texas Health Science Center at San Antonio
Air Force Village I

You have been asked to participate in a research study to determine if the presence of an advance directive document increases the accuracy of the substituted judgments of a surrogate decisionmaker. I hope to learn if having an advance directive helps individuals to communicate their wishes to their proxy and if the proxy is better able to understand those wishes.

If you decide to participate, I, Nina Watson, RN, will ask you to complete a demographic survey and a questionnaire regarding four scenarios depicting end-of-life situations and possible treatments that may or may not be given in that situation. You will be asked to choose the option for treatment that *you think the one for whom you are making decisions would want in that situation*. Your participation will take approximately one hour. I will review the questionnaires with you and explain any words you do not understand. I ask that you do not discuss the scenarios as you complete the questionnaire. If you like, upon completion of the questionnaires, I will go over your answers with you and answer any questions you may have.

The possible benefits of this study will be recognition of the importance of communicating the type of medical preferences you have in the event you become unable to make them for yourself. I cannot and do not guarantee or promise that you will receive any benefits from this study. There should be no discomfort or adverse conditions experienced. There will not be any financial compensation given.

Any information obtained in regards to this study that can be identified with you will remain confidential. Your questionnaires will be numbered so I can identify the person with the advance directive and the designated or acting proxy. If I publish the results of the study in a scientific magazine or book, I will not identify you in any way.

Your participation is voluntary and you may withdraw from the study at any time.

If you have any questions, ask me. If you have any additional questions later, you may call me, Nina Watson, at 830-303-2631 (this is a San Antonio metro phone number and not long distance). You may also contact the University of Texas Health Science Center Institutional Review Board (567-2351) if you have any questions, comments, or concerns about the study or your rights as a research participant.

You will be given a copy of this consent form to keep.

YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO TAKE PART IN THIS RESEARCH STUDY AND THAT YOU HAVE READ AND UNDERSTAND THE INFORMATION GIVEN ABOVE AND EXPLAINED TO YOU.

Date: _____

 Signature of Witness

 Signature of Investigator

 Signature of Participant

Name: _____

Address: _____

Phone #: _____

Birthdate: _____

SUBJECT CONSENT TO TAKE PART IN A STUDY OF
The Accuracy of a Proxy's Substituted Judgments for Individuals with and without Advance Directives
The University of Texas Health Science Center at San Antonio
Air Force Village II

You have been asked to participate in a research study to determine if the presence of an advance directive document increases the accuracy of the substituted judgments of a surrogate decisionmaker. I hope to learn if having an advance directive helps individuals to communicate their wishes to their proxy and if the proxy is better able to understand those wishes.

If you decide to participate, I, Nina Watson, RN, will ask you to complete a demographic survey and a questionnaire regarding four scenarios depicting end-of-life situations and possible treatments that may or may not be given in that situation. You will be asked to choose the option for treatment that *you think the one for whom you are making decisions would want in that situation*. Your participation will take approximately one hour. I will review the questionnaires with you and explain any words you do not understand. I ask that you do not discuss the scenarios as you complete the questionnaire. If you like, upon completion of the questionnaires, I will go over your answers with you and answer any questions you may have.

The possible benefits of this study will be recognition of the importance of communicating the type of medical preferences you have in the event you become unable to make them for yourself. I cannot and do not guarantee or promise that you will receive any benefits from this study. There should be no discomfort or adverse conditions experienced. There will not be any financial compensation given.

Any information obtained in regards to this study that can be identified with you will remain confidential. Your questionnaires will be numbered so I can identify the person with the advance directive and the designated or acting proxy. If I publish the results of the study in a scientific magazine or book, I will not identify you in any way.

Your participation is voluntary and you may withdraw from the study at any time.

If you have any questions, ask me. If you have any additional questions later, you may call me, Nina Watson, at 830-303-2631 (this is a San Antonio metro phone number and not long distance). You may also contact the University of Texas Health Science Center Institutional Review Board (567-2351) if you have any questions, comments, or concerns about the study or your rights as a research participant.

You will be given a copy of this consent form to keep.

YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO TAKE PART IN THIS RESEARCH STUDY AND THAT YOU HAVE READ AND UNDERSTAND THE INFORMATION GIVEN ABOVE AND EXPLAINED TO YOU.

Date: _____

 Signature of Witness

 Signature of Investigator

 Signature of Participant

Name: _____

Address: _____

Phone #: _____

Birthdate: _____

SUBJECT CONSENT TO TAKE PART IN A STUDY OF
The Accuracy of a Proxy's Substituted Judgments for Individuals with and without Advance Directives
The University of Texas Health Science Center at San Antonio
Community of Seguin, Texas

You have been asked to participate in a research study to determine if the presence of an advance directive document increases the accuracy of the substituted judgments of a surrogate decisionmaker. I hope to learn if having an advance directive helps individuals to communicate their wishes to their proxy and if the proxy is better able to understand those wishes.

If you decide to participate, I, Nina Watson, RN, will ask you to complete a demographic survey and a questionnaire regarding four scenarios depicting end-of-life situations and possible treatments that may or may not be given in that situation. You will be asked to choose the option for treatment that *you think the one for whom you are making decisions would want in that situation*. Your participation will take approximately one hour. I will review the questionnaires with you and explain any words you do not understand. I ask that you do not discuss the scenarios as you complete the questionnaire. If you like, upon completion of the questionnaires, I will go over your answers with you and answer any questions you may have.

The possible benefits of this study will be recognition of the importance of communicating the type of medical preferences you have in the event you become unable to make them for yourself. I cannot and do not guarantee or promise that you will receive any benefits from this study. There should be no discomfort or adverse conditions experienced. There will not be any financial compensation given.

Any information obtained in regards to this study that can be identified with you will remain confidential. Your questionnaires will be numbered so I can identify the person with the advance directive and the designated or acting proxy. If I publish the results of the study in a scientific magazine or book, I will not identify you in any way.

Your participation is voluntary and you may withdraw from the study at any time.

If you have any questions, ask me. If you have any additional questions later, you may call me, Nina Watson, at 830-303-2631 (this is a San Antonio metro phone number and not long distance). You may also contact the University of Texas Health Science Center Institutional Review Board (567-2351) if you have any questions, comments, or concerns about the study or your rights as a research participant.

You will be given a copy of this consent form to keep.

YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO TAKE PART IN THIS RESEARCH STUDY AND THAT YOU HAVE READ AND UNDERSTAND THE INFORMATION GIVEN ABOVE AND EXPLAINED TO YOU.

Date: _____

 Signature of Witness

 Signature of Investigator

 Signature of Participant

Name: _____

Address: _____

Phone #: _____

Birthdate: _____

Demographic Data**Sex:** M F **Age:** _____ **Marital Status:** S M D W**Education:** grade school high school college graduate or above**Ethnicity:** White Black Hispanic Asian Other**Religion:** Catholic Protestant Jewish Other _____**Advance Directive Document:** None Living Will Power of Attorney Both**I have/have not completed an advance directive because:**
_____**My designated proxy is:** my spouse a family member friend**I have discussed my decisions regarding health care at end of life with:**

my proxy my spouse my children other relatives my physician close friends

These discussions were:

casual general purposeful very in-depth and specific

We have had these discussions:

never once 2-5 times 6-10 times >10 times

I have been hospitalized in the last year: yes no**I have a chronic illness:** yes no**I consider my health to be:**

very poor poor fair good excellent

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VITA

Nina Ann Watson was born to Gaynel and Annie Patterson, March 16, 1953 at Balboa Naval Hospital, San Diego, California. She graduated from Seguin High School in 1971. She married Huey Watson on August 18, 1973. Her husband joined the Air Force shortly after they were married which gave her the opportunity to live in such places as the Philippines and Germany. They have two sons. John was born December 7, 1974 at Wilford Hall Medical Center, San Antonio, Texas. Joshua was born March 30, 1976 at Vandenberg AFB, California. She completed Licensed Vocational Training at St. Phillips College, San Antonio, Texas, in 1979, graduating at the top of her class. She graduated, cum laude, from the University of New Mexico, Albuquerque, New Mexico in 1987 with a Bachelor of Science in Nursing. Upon graduation, she was sworn in as a nurse in the United States Air Force. Her military nursing career includes: a multiservice unit at Kirtland AFB, New Mexico; Special Care Unit at Elmendorf AFB, neurotrauma ICU at Wilford Hall Medical Center, San Antonio, Texas, and her current assignment as a graduate student at the University of Texas Health Science Center in San Antonio. She will be assigned to Keesler AFB, Mississippi as the Diabetic Educator upon graduation. She entered UTHSCSA in August 1996 to pursue a graduate degree in Acute Care of the Adult Patient. She is certified as a Critical Care Nurse. She is a member of the American Nurses Association, American Association of Critical-Care Nurses, Sigma Theta Tau, American Society of Pain Management Nurses, and the American Diabetes Association.